

Communication of Preferences for Care Among Human Immunodeficiency Virus–Infected Patients

Barriers to Informed Decisions?

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Objective: To examine the way patients with serious, progressive illnesses communicate their care preferences to their physician.

Design: An observational, cross-sectional survey of 1031 clients with acquired immunodeficiency syndrome (AIDS) or symptomatic human immunodeficiency virus disease. Self-report of communication was assessed in 861 clients who stated a treatment preference focused on extending life or focused on comfort even if it shortened life.

Setting: The Robert Wood Johnson AIDS Health Services Program in 9 US cities.

Participants: Eight hundred sixty-one of 1031 clients recruited to the AIDS Health Services Program.

Results: Eight hundred sixty-one subjects expressed a preferred treatment approach; however, only 35.8% had

spoken to their physician about their preferred treatment. Black clients were half as likely (odds ratio, 0.49; confidence interval, 0.29-0.85) to have discussed their preferred treatment approach even after adjustment for age, function, education, income, and other covariates. Black clients were half as likely to prefer an approach to care that focused only on comfort (odds ratio, 0.51; 95% confidence interval, 0.34-0.76). Clients with AIDS who were symptomatic daily, college educated, and more functionally impaired were more likely to have discussed a preferred treatment approach with their physician.

Conclusions: Most persons with symptomatic human immunodeficiency virus infection have not discussed their preferred treatment approach with a physician. This disparity is greater for blacks, who were less likely to want a palliative treatment approach.

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MEDICAL treatment decisions are part of every clinician's practice. These decisions require a physician and patient to come to an understanding about the goals of care. This understanding influences treatment decisions ranging from diagnostic testing to the withdrawal of life-sustaining therapies, and treatment decisions are being made routinely in the care of seriously ill patients. During the past 4 decades, professional and public groups have endorsed the idea that medical decisions should reflect patients' informed preferences, embracing the idea that patients have the right to all the information necessary to participate in medical decisions.¹⁻³ As for patients themselves, most want to know about recommended treatments, the possible outcomes of those treatments, and possible alternatives to the recommended treatments.⁴⁻⁶ Without adequate discussion, the medical care that physicians render may be

inconsistent with the patient's preferences. This inconsistency also can lead to poorer health outcomes.^{7,8} Open discussion between physicians and their patients is required to provide the opportunity to incorporate patients' preferences.

However, clear communication between patients and physicians often does not occur. Caralis et al⁹ showed that although 54% of their study population wanted discussions about end-of-life treatment preferences, only 14% had discussed their preferences with a physician. Haas et al¹⁰ showed that only 38% of patients with acquired immunodeficiency syndrome (AIDS) discussed their preferences with their physician.

Patient characteristics such as race and socioeconomic status may influence the preference for and goals of medical care.¹¹⁻¹⁵ These previous studies were limited by the small number of nonwhites (N=12) in the study by Haas et al¹⁰ and possible confounding by disease severity and depression in the study by Caralis et

PATIENTS AND METHODS

This study is an observational, cross-sectional survey of the clients of the AIDS Health Services Program funded by the Robert Wood Johnson Foundation. This program was a multisite demonstration of community-based care for people with HIV-related illness. The AIDS Health Services Program, as described previously,^{16,17} had 2 main goals: developing coordinated networks of agencies to provide health and social service for patients afflicted with HIV-related illnesses, and facilitating comprehensiveness and continuity of care through case management. This study was approved by the institutional review board at Brown University, Providence, RI.

STUDY POPULATION

Personal interviews were conducted with 1031 clients of the AIDS Health Services Program in the following communities: Nassau County, New York; Newark and Jersey City, NJ; Fort Lauderdale and Miami, Fla; Atlanta, Ga; New Orleans, La; Dallas, Tex; and Seattle, Wash. To be eligible for the survey, respondents had to be at least 18 years old and clients of the AIDS Health Services Program for at least 1 month. To preserve confidentiality, clients could not be contacted directly. Instead, we used direct service providers (usually the client's case manager) as intermediaries to make the request to participate in the study, as described previously.¹⁸ Respondents were recruited from the local community-based organization providing social services to people with AIDS and from participating hospitals' outpatient clinics. The interviews were conducted by professional survey interviewers trained for this protocol.

Of these 1031 clients, 861 clients who responded to the question, "In thinking about yourself, if you had to pick 1 approach, which of these 2 approaches do you want to take in your medical treatment?"¹¹ were included in the

analysis. The response categories included "an approach that focuses on extending life even if it causes pain and suffering" or "an approach that focuses on relieving pain even if it shortens your life."¹⁹ Communication of a treatment preference was determined by asking the respondents the following question, "Have you told your physicians that this is the approach you want taken in your treatment?" The respondents were asked to answer yes, no, or don't know. A total of 127 clients were excluded from the multivariate analysis because they answered "don't know" to whether they had talked to their physician about a preferred approach to care (n=7) or missing data on 1 or more of the independent variables (n=120). Respondents excluded from the analysis did not differ from other respondents by diagnosis of AIDS, income, function, risk group, depression, symptom severity, presence of a primary relationship, and number of confidants.

INDEPENDENT VARIABLES

The independent variables used in this study were chosen from the following domains: demographic (race, sex, education, risk group, and income); social (perceived social support, having a confidant, and relationship status); function and medical (diagnosis of AIDS or not, symptoms in the past 3 months, and depression). For race, the respondents were asked to report their ethnic group from the following responses: white or Caucasian, black, Asian or Pacific Islander, American Indian, or Alaskan Native. They were asked a second question about whether they were of Hispanic origin or descent. For this analysis, we used respondents who stated they were black or white without Hispanic heritage. Those who were neither black nor white without Hispanic heritage were categorized as other. Level of education was categorized as having less than a high school degree, high school or technical school degree, or at least some college or graduate school training.

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al.⁹ In the present study, we seek to determine which factors are associated with the preferences of care in human immunodeficiency virus (HIV)-positive patients and which factors are linked to adequate or inadequate physician-patient communication about these preferences.

RESULTS

Subjects, for the most part, were young (average age, 35 years; range, 18-67 years) men (90.1%) with AIDS (87.7%), and with the predominant risk factor for HIV transmission being through a homosexual relationship (70.4%) (**Table 1**). Almost one third of the subjects were nonwhite, with 21.3% black and 12.5% from other racial groups. More than half had some college training. Fifty-five percent had a negative screen for depression on the Center for Epidemiologic Studies-Depression scale. Most subjects (59.5%) had low social supports and no spouse or significant partner (62.0%). However, most subjects (80.5%) had at least 1 person in whom they could confide (confidant). Most subjects (77.8%) experienced HIV-related symptoms on at least a weekly basis and

slightly more than one third experienced functional limitations due to their disease.

COMMUNICATION OF PREFERENCES

Of the 861 subjects in our sample, only 35.8% reported discussing a preferred treatment approach with their physician (**Table 2**). For subjects with full-blown AIDS (n=755), only 38.9% discussed their preferred treatment approach. Blacks were significantly less likely to have spoken to their physician than were whites, as were those with lower education, lower income, and less frequent symptoms.

The multivariate analysis examining the factors associated with HIV-infected persons of having discussed their preferred treatment approach with their physician is given in **Table 3**. Even after controlling for other variables, blacks were less likely to have discussed a preferred treatment approach with their physician (adjusted odds ratio [AOR], 0.49; 95% confidence interval [CI], 0.29-0.85). Subjects with AIDS (AOR, 3.46; 95% CI, 1.62-7.42), who were college educated (AOR, 1.93; 95% CI, 1.11-3.34), who were more functionally

Respondents reported their HIV risk group by indicating whether they were an injecting drug user or homosexual or bisexual. Income was assessed by having the respondents indicate their income range for the past month or its yearly equivalent. They chose from 15 different income ranges, and this scale was collapsed to the following: \$0 to \$6000, \$6001 to \$15 600, \$15 601 to \$21 000, and more than \$21 000. To measure perceived instrumental social support, respondents were asked how likely it would be for at least 1 of their friends or relatives to provide assistance with each of 7 tasks: help with household chores, help with bathing or dressing, providing transportation, loaning \$100, giving advice, providing a place to stay for a few days, and providing a place to stay for several weeks.¹⁹ Respondents answered whether assistance was "very," "somewhat," "not very," or "not at all" likely. Those who perceived assistance with all 7 tasks as very likely were classified as having high social support; those who thought that assistance was somewhat of a problem with at least 1 task were classified as having low social support. In addition, 2 measures of emotional support were created. First, those involved in a long-term committed relationship (including marriage) were compared with those not involved in such a relationship. Second, respondents also indicated whether they had at least 1 friend with whom they could discuss personal feelings and problems.

Function was assessed by asking about the degree of difficulty encountered in performing the following 6 activities: shopping or doing small errands without help, doing cleaning or heavy housework, walking up 10 steps without resting, lifting or carrying 2 full bags of groceries, walking 0.402 km (a quarter mile), or getting around town.¹⁹ Respondents chose among the following response categories: "not at all hard," "not very hard," "somewhat hard," "very hard," and "impossible," which were trichotomized into those who had no difficulties (ie, stating not at all hard

or not very hard), those with difficulties on 1 task, or 2 or more tasks. Based on self-report, disease stage was dichotomized as having AIDS vs having AIDS-related complex or just being antibody-positive.

Symptom intensity was measured by asking how often in the past 3 months respondents had experienced each of the 9 specific medical conditions: trouble remembering, seizures, weakness, fevers, chills, night sweats, shortness of breath, diarrhea, and weight loss. Frequency was recorded on a 5-point scale (daily, several times a week, weekly, once or twice, or never). A scale of symptom intensity was constructed by summing the number of experienced symptoms, each weighted by its frequency. This scale was trichotomized for purposes of analysis based on its distribution.

Depression was categorized using a total score from the Center for Epidemiologic Studies-Depression scale, a screening instrument for depression, and analyzed based on the cut points recommended by the authors.^{20,21}

ANALYSIS

We assessed the bivariate associations of communication of preferences for an approach to care with each independent variable using the χ^2 test for nominal variables. To examine the associations for communication of a specific preference while controlling for potential confounding variables, we performed a backward stepwise multivariate logistic regression analysis. The equation predicts the response of having communicated a preferred approach to care to one's physician. The criterion to enter the model was an α of .05, and the criterion to exclude was an α of .10. All of the remaining respondents in our analysis had expressed a treatment preference that focused on extending life or relieving pain. All analyses were performed on a commercially available software package (Statistical Package for the Social Sciences, version 3.1).²²

impaired (AOR, 1.55; 95% CI, 1.02-2.35), and who had symptoms daily (AOR, 1.81; 95% CI, 1.07-3.04) were more likely to have discussed a preferred treatment approach with their physician.

TREATMENT PREFERENCES

White respondents were somewhat more likely to prefer a treatment approach focused on relieving pain (71%); black respondents were split evenly between the 2 approaches. Respondents who were homosexual or bisexual, had at least 1 confidant, had been diagnosed as having AIDS, had some college education, or were male also were more likely to prefer an approach that focused on relieving pain (**Table 4**).

When examining the multivariate associations for this preference, we found that blacks were 0.51 times less likely to prefer a treatment approach that focused on relieving pain as opposed to extending life (95% CI, 0.34-0.76), controlling for other covariates (**Table 5**). Respondents who were homosexual or bisexual were 1.42 times more likely to prefer an approach that focused on relieving pain (95% CI, 0.94-2.14). Female respondents and those who had a negative screening score for de-

pression also were less likely to prefer an approach that relieves pain.

COMMENT

Our study confirms previous findings that communication of treatment preferences differs between whites and blacks,^{9,10,16} even after adjustment for socioeconomic status and disease severity. These results also reinforce our previous findings that communication is associated with whether patients reported a care plan consistent with their preferred treatment approach.^{16,23} Most subjects with a serious, often fatal illness have not discussed their preference for an approach to care with their physician. However, subjects who were diagnosed as having the more severe AIDS, who had higher socioeconomic status, and who had greater functional difficulty were more likely to have discussed with their health provider their treatment preference.

Our findings also are consistent with a study by Haas et al,¹⁰ which showed that only 38% of patients with AIDS discussed their preferences with their physician. Our current findings call for further research to understand these differences.

Table 1. Sample Description of 861 Subjects*

Variable	No. (%) of Subjects
Race	
White	562 (66.2)
Black	181 (21.3)
Other	106 (12.5)
Education	
Less than high school	155 (18.1)
High school diploma	247 (28.9)
Some college or more	454 (53.0)
Homosexual or bisexual	
Yes	596 (70.4)
No	250 (29.6)
Injecting drug user	
Yes	309 (36.5)
No	537 (63.5)
Income, \$	
0-6000	457 (54.1)
6001-15 600	279 (33.1)
15 601-21 000	53 (6.3)
>21 000	55 (6.5)
Social support	
Low	483 (59.5)
High	329 (40.5)
Acquired immunodeficiency syndrome	
Yes	755 (87.7)
No	106 (12.3)
Primary relationship	
Yes	326 (38.0)
No	531 (62.0)
No. of confidants	
None	167 (19.5)
≥1	689 (80.5)
Function	
No difficulties	544 (63.5)
Difficulty in 1 task	97 (11.3)
Difficulty in 2 or more tasks	216 (25.2)
Depression score	
Positive	380 (44.7)
Negative	470 (55.3)
Preferred approach	
Extend life	294 (34.1)
Relieve pain	567 (65.9)
Has told physician about preference	
Yes	306 (35.8)
No	548 (64.2)
Sex	
Male	776 (90.1)
Female	85 (9.9)
Frequency of symptoms	
Infrequent	185 (22.2)
Weekly	357 (42.7)
Daily	293 (35.1)

*All categories do not add up to 861 because of missing data.

One potential explanation is that blacks historically have had different access to, and generally poorer, health care.²⁴⁻²⁶ Furthermore, socioeconomic status has been shown to limit access to care and to be a risk for receiving substandard medical care.²⁷⁻³² People who are uninsured or have lower income are less likely to undergo surgery and cardiac procedures.^{28,29} Even gender has led to differential utilization.^{33,34}

The black community's awareness of these differences may engender a lack of trust between them and

Table 2. Communication of Preferences

Variable	No. of Subjects	No. (%) of Subjects Who Told Physician About Treatment Preference	P
Race			
White	558	238 (42.7)	<.001
Black	181	33 (18.2)	
Other	105	33 (31.4)	
Acquired immunodeficiency syndrome			
Yes	749	294 (39.3)	<.001
No	105	12 (11.4)	
Education			
Less than high school	155	32 (20.6)	<.001
High school diploma	245	74 (30.2)	
Some college or more	450	200 (44.4)	
Income, \$			
0-6000	457	134 (29.3)	<.001
6001-15 600	275	122 (44.4)	
15 601-21 000	53	23 (43.4)	
>21 000	55	24 (43.6)	
Function			
No difficulties	538	173 (32.2)	<.05
Difficulty in 1 task	97	40 (41.2)	
Difficulty in 2 or more tasks	215	90 (41.9)	
Frequency of symptoms			
Infrequently	184	47 (25.5)	<.001
Weekly	353	122 (34.6)	
Daily	292	130 (44.5)	
Homosexual or bisexual			
Yes	596	239 (40.1)	<.001
No	250	65 (26.0)	
Injecting drug user			
Yes	309	107 (34.6)	<.07
No	537	197 (36.7)	
Social support			
Low	483	176 (36.4)	<.10
High	329	118 (35.9)	
Primary relationship			
Yes	326	121 (37.1)	<.05
No	531	185 (34.8)	
No. of confidants			
None	167	45 (26.9)	<.03
≥1	689	261 (37.8)	
Depression score			
Positive	380	150 (39.4)	<.03
Negative	470	152 (32.3)	
Sex			
Male	776	286 (36.8)	<.03
Female	85	20 (23.5)	
Type of preference			
Extend life	292	95 (32.5)	<.02
Relieve pain	562	211 (37.5)	

their medical providers or health care institutions. Some blacks and persons of lower socioeconomic status may believe that health providers want to "experiment" on them, especially if care is received at an institution that conducts human research.^{35,36} These groups also may be equating "life-support" with "life," and any effort to withhold life-sustaining therapies may be seen as genocide.³⁷

Our findings may be a reflection of the lack of an ongoing relationship with a primary care physician. Sub-

Table 3. Multivariate Results for Prediction of Communication of a Preference for Care

Independent Variable	Adjusted Odds Ratio	95% Confidence Interval
Race		
White	1.00	...
Black	0.49	0.29-0.85
Other	0.84	0.48-1.45
Acquired immunodeficiency syndrome		
Yes	3.46	1.62-7.42
No	1.00	...
Education		
Less than high school	1.00	...
High school diploma	1.26	0.71-2.24
Some college or more	1.93	1.11-3.34
Income, \$		
0-6000	1.00	...
6001-15 600	2.02	1.40-2.92
15 601-21 000	1.71	0.85-3.44
>21 000	2.25	1.14-4.45
Function		
No difficulties	1.00	...
Difficulty in 1 task	1.44	0.84-2.47
Difficulty in 2 or more tasks	1.55	1.02-2.35
Frequency of symptoms		
Infrequently	1.00	...
Weekly	1.03	0.65-1.65
Daily	1.81	1.07-3.04

Table 4. Association With a Preference for an Approach to Care

Independent Variable	Extend Life, No. (%)	No. (%) Who Chose to Relieve Pain	P
Race			
White	163 (29.0)	399 (71.0)	<.001
Black	90 (49.7)	91 (50.3)	
Other	36 (34.0)	70 (66.0)	
Acquired immunodeficiency syndrome			
Yes	247 (32.7)	508 (67.3)	.02
No	47 (44.3)	59 (55.7)	
Homosexual or bisexual			
Yes	173 (29.0)	423 (71.0)	<.001
No	114 (45.6)	136 (54.4)	
Sex			
Male	247 (31.8)	529 (68.2)	<.001
Female	47 (55.3)	38 (44.7)	
Education			
Less than high school	68 (43.9)	87 (56.1)	.006
High school diploma	88 (35.6)	159 (64.4)	
Some college or more	136 (30.0)	318 (70.0)	
No. of confidants			
None	66 (39.5)	101 (60.5)	.11
≥1	225 (32.7)	464 (67.3)	

jects who are black or of lower socioeconomic status are less likely to have an ongoing relationship with a primary care physician.³⁸ Also, blacks may perceive their physicians as authoritarian and someone with whom they cannot communicate.³⁹ In addition, some subjects may

Table 5. Multivariate Results for Prediction of a Palliative Preference for Care

Independent Variable	Adjusted Odds Ratio	95% Confidence Interval
Race		
White	1.00	...
Black	0.51	0.34-0.76
Other	0.90	0.55-1.48
Age	1.02	1.00-1.05
Sex		
Male	1.00	...
Female	0.49	0.27-0.91
Depression		
Yes	1.00	...
No	0.82	0.70-0.97
Homosexual or bisexual		
Yes	1.42	0.94-2.14
No	1.00	...

resent and distrust any person in a position of power over their lives.⁴⁰ Viewing the physician as an authority figure may foster further distrust in this community, leading them to be less receptive to discussions about limiting treatment. Furthermore, distrust limits the ability to establish an adequate patient-physician relationship and lowers the chance that sensitive issues such as treatment preferences will be discussed.

Another potential reason for these findings may be the barrier that religious differences pose to end-of-life discussions. In 1 study, 40% of blacks indicated that religion influenced how they felt about death.³⁷ Lincoln^{41,42} points out that some blacks subscribe to a "black theology" that embraces notions of man's responsibility to work with God and man's faith that God can handle any problem exclusively. Differing religious attitudes, promoting an attitude of resilient hope in spite of overwhelming odds, may reflect the legacy of oppression left on the consciousness of some black patients. These feelings can become a barrier to the discourse necessary for adequately shared decision making. The unknown effect that individual beliefs combined with personal life experiences has on the decision-making process mandates the need to address these issues. Physicians should understand that some patients may hesitate to discuss their treatment preferences if a comfortable relationship is not developed.

For lower socioeconomic groups, patient-physician communication may be less open because of perceived differences in socioeconomic status. Kavanagh and Kennedy⁴³ state that health care providers have a generalized preference for clients who are similar to themselves and who represent societal ideals. Therefore, it is common to encounter resistance in communication with diverse clients when situations involve complex, inequitable circumstances.⁴⁴ Patients with higher socioeconomic status may feel a greater ability for self-expression, allowing them to be more comfortable communicating with health professionals. They tend to be more "enfranchised" and have greater overall access to the medical care of their choosing. Our findings of lower communication rates in

persons of lower education and lower income support these previous studies.

Furthermore, patients with a more serious illness have a greater need for direction about treatment preferences. Persons with AIDS who are functionally impaired and experiencing more AIDS-related symptoms will be, in the short term, facing decisions about end-of-life therapy. This urgency may be driving more communication of preferences despite other barriers. Also, the progression of a chronic disease, such as HIV infection, may lead to a re-evaluation of assumed treatment goals, necessitating clearer communication between these patients and their health provider for continued care. In our study, subjects with full-blown AIDS were the most likely to communicate treatment preferences to their physician even when controlling for other variables. Also, physicians caring for these subjects may be more likely to initiate the conversation and encourage full communication about treatment preferences. More research is needed to explain more fully the effect of disease severity on the timing of the discussion of treatment preferences.

Our study has limitations. First, the respondents were clients of the AIDS Health Services Programs and as such, a select, nonrandomized population more likely to be connected to the health care system. Therefore, the results may not reflect differences generalizable to respondents who are not in this group. Second, preferences obtained at one point in time and under research conditions may not reflect respondents' preferences when the decision is a reality. Also, as patients progress through different stages of illness, their preferred treatment approach and their communication pattern may change. Finally, it is possible that different groups of respondents systematically misinterpreted the questions. Despite these limitations, our study suggests that the communication of a preferred treatment approach is lacking, especially in blacks, persons of lower socioeconomic status, those who have less severe disease, and those who are functioning better.

Future research is needed to understand these findings and the ways to improve discussions about treatment preferences as part of routine practice. Without this research, we can only speculate about the potential reasons for these study results.

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